

In memory of Madeline

After losing their youngest daughter to cancer, the Adams family joined the fight to find a cure

By Robyn Bradley Litchfield • May 30, 2010

A spunky little blonde, Madeline Adams of Montgomery was 3 years old when her parents began to see subtle changes in her behavior.

There were restless nights, more potty accidents, excessive eye blinking and other things that just seemed a bit *off*, said Madeline's mom, Elizabeth Adams. Nothing, however, appeared to be serious enough to warrant a trip to the pediatrician, at least, not at first. But when Madeline woke up and her entire left side was limp, Adams and her husband, Pat, rushed her to the doctor's office, assuming that their youngest child had suffered a stroke.

When a CT scan revealed a mass in Madeline's brainstem, the Adamses would discover that her condition was far worse. Following an MRI at Children's Hospital of Alabama (in Birmingham), a seasoned neurologist, with hands trembling, broke the news: Madeline had diffuse intrinsic pontine glioma (DIPG), a rare and incurable form of pediatric brain cancer.

"And here I was, thinking that leukemia was the worst thing that could happen to a child, but my child has something much worse," Elizabeth Adams thought as she and her husband faced this deadly disease. Actually, 90 percent of children who have leukemia survive, which is the opposite for children with DIPG.

The Adamses dream of the day when those percentages change and a cure is found. They are heavily involved in The Cure Starts Now (CSN) Foundation, a non-profit organization established about three years ago by Keith and Brooke Desserich, whose 6-year-old daughter Elena died from the same disease. (The Desserichs released a book titled "Notes Left Behind" with notes that Elena left for her family.) The families got to know each other when Madeline and Ellie were being treated at the same time at St. Jude Children' Research Hospital in Memphis.

The Cure Starts Now is made up of volunteers who

want to help fund the cure for pediatric brain cancer, Elizabeth Adams said.

"The foundation's directors are driven and determined and enthusiastic about this goal," she said. "Amazing things are beginning to happen in the world of pediatric brain cancer research because of CSN's initiative."

So far, the foundation has funded more than \$40,000 in pediatric brain cancer research and treatments. In 2010, CSN has funded three studies, including "Phase I Study of Tumor-Targeting Convection-Enhanced Delivery for Diffuse Pontine Gliomas in Children" at Cornell University.

Dr. Mark Souweidane from Cornell is attempting to implant tiny catheters into the tumor directly using MRI to guide placement and deliver medication directly, Adams said.

Madeline's dad, Pat Adams, serves on the foundation's medical advisory board and said one of the goals is to facilitate cooperation among various physicians and researchers.

"We are trying to get them to work together more, rather than have different people spending time and money on the same work," he said.

Though it is gratifying to be involved in the foundation's work, the experience is bittersweet for the Adams family.

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Their little Madeline spent the final 11 months of her short life enduring radiation and drug tests, and the tumors grew back, which was both disheartening and devastating. During her treatment, the little girl's parents felt completely helpless. At one point, her dad even said they had a better chance of sending Madeline to the moon.

Those final months, the little girl gradually lost the ability to swallow, speak or communicate. She became completely paralyzed on the left side, and the Adamses said she was just miserable in her own little body.

Before she got sick, Madeline was somewhat of a tomboy, but she also enjoyed playing dress up, with "shows" and pretend balls. Her favorite outfits included one of her big brother's old T-shirts, blue-jean shorts and her big sister's pink cowboy boots.

Elizabeth Adams said their youngest daughter had a way of making everybody smile.

"She just had a way of doing things and saying things that made you laugh," she said. "I had a hard time disciplining her because most of the time I would have to turn around, try to stop laughing without her seeing me, and then, by the time I turned around again, either she had escaped or she could tell I was laughing."

And though the little girl was relatively fearless, loved to go anywhere and was game for just about anything, she was terrified of doctors.

"Unfortunately, she spent the last year of her life in many doctors' offices," Elizabeth Adams said.

The Adamses are determined to do what they can to help find a cure for DIPG. They know firsthand how difficult it is to sit with a top pediatric neuro-oncologist and realize the physicians feel almost as helpless as the parents.

And, she said, it's disappointing to see how little funding is given to pediatric cancer, particularly brain cancer -- despite the fact that brain cancer is the most deadly of pediatric cancers and pediatric cancer is the No.1 cause of death by disease in ages 20 and younger, she said, adding that the number

of diagnoses each year is on the rise.

Losing a child to the disease, the Adamses know all about how devastating it is when nobody in the nation has medicine proven to cure the disease.

"We know how frustrating it is to realize that your only thin piece of hope in the world of medicine is a phase-one drug trial that was originally intended for another form of cancer," Elizabeth Adams said. "We want to see changes in the world of pediatric brain cancer for the patients and the parents."



The Adams, Elizabeth, left, Pat and Ellie, talk with visitors at their "Make A Stand" lemonade stand in front of Nancy's Italian Ice. (Lloyd Gallman)

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Madeline Adams lost her battle with diffuse intrinsic pontine glioma at the age of 4. (Contributed)

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What: Diffuse intrinsic pontine glioma affects the pons portion of the brainstem, and renders nervous system function impossible. Symptoms include double vision, inability to close the eyelids completely, inability to swallow and paralysis. Survival is rare. In fact, less than 10 percent of DIPG children live longer than 18 months from diagnosis.

Getting involved: The Cure Starts Now Foundation, a federal 501c(3) non-profit charity organization, has 12 chapters around the nation (including Alabama) and was established in honor of Elena Desserich. Its mission is to raise awareness and funds to find cures for brainstem glioma and other forms of pediatric brain cancer.

Information: Call visit www.thecurestartsnow.org

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